

## What can I do to help prevent health problems related to sickle cell disease?

Parents of children with sickle cell disease should make sure that their child:

- Gets **regular health check-ups**
- Drinks plenty of **fluids**
- Gets enough **oxygen**
- Gets plenty of **rest**
- Takes daily **medications and vitamins** (including folic acid)
- Avoids getting too hot or cold
- If your child is under the age of six, make sure he or she takes **penicillin** every day.

Your child's doctor can answer any other questions about risks your child may have when playing sports or other activities.

## Who can I talk to about sickle cell disease?

### Indiana Hemophilia & Thrombosis Center

8402 Harcourt Rd., Suite 500  
Indianapolis, IN 46260  
**(317) 871-0000**

Clinic and Education Center

### Riley Hospital for Children

702 Barnhill Dr.  
Indianapolis, IN 46202  
**(317) 274-8784**

### Indiana State Department of Health

2 North Meridian Street, 7F  
Indianapolis, IN 26204  
**(888) 815-0006**

### Sickle Cell Disease Association of America, Inc.

Website: [www.sicklecelldisease.org](http://www.sicklecelldisease.org)



Indiana State  
Department of Health

## What is Sickle Cell Disease?



*Currently, about 72,000 people in the United States have sickle cell disease; each year, about 1,000 babies are born with sickle cell disease. Although most people with sickle cell disease are African-Americans, people of other ethnic groups can also have sickle cell disease.*

### What is sickle cell disease?

**Sickle cell disease** is part of a group of conditions called **hemoglobinopathies**. Hemoglobinopathies are conditions that occur when a person has a change in a protein called **hemoglobin**. Our blood cells use hemoglobin to carry oxygen from our lungs to other parts of the body. When a person has sickle cell disease, his or her blood cells change shape. Instead of the red blood cells being round and flexible, the red blood cells become curved and stiff with a sickle shape like this: ( . Instead of passing through the blood easily, sickle cells get “stuck” in the body’s blood vessels. When the sickle cells are stuck, the body’s tissues don’t get enough oxygen.

### What causes sickle cell disease?

Sickle cell disease is an **inherited** (passed from parent to child) condition. Everyone inherits two copies of the hemoglobin

gene (one from our mothers and one from our fathers). When the hemoglobin gene is changed, the gene cannot work properly. People with **sickle cell disease** have two sickle cell gene changes. People with **sickle cell trait** have one sickle cell gene change.

### What health problems do people with sickle cell disease have?

People with sickle cell disease can have health problems including pain, infections, and damage to the body’s organs. When the sickle cells get “stuck” in the body, a person can have an **episode** or **crisis**. Symptoms of an episode or crisis may include:

- Shortness of breath
- Dizziness
- Headache
- Coldness in the hands and feet
- Pale skin
- Chest pain
- Swelling

### How is sickle cell disease treated?

There is no cure for sickle cell disease. Sickle cell disease is a lifelong illness, but it can be treated. Most patients with sickle cell disease will take **penicillin** to lower the chance that an episode will happen. Early intervention is important—people with sickle cell disease who start taking penicillin early in life have fewer episodes.

### Children with sickle cell disease

Most babies with sickle cell disease usually do not have symptoms until they are 4 – 6 months old. Parents of children with sickle cell disease should learn how to:

- Recognize the features or symptoms of sickle cell disease.
- One of the first symptoms to be recognized in infants is **Hand-Foot Syndrome**. This occurs when a person’s hands and feet do not receive enough blood. People who have Hand-Foot Syndrome may have pain and swelling of the hands and feet.
- Know when to seek immediate medical care. People who are having an episode or crisis and need to see a doctor may have some of the following symptoms:
  - Shortness of breath
  - Coldness in the hands or feet
  - Pale skin

Children with sickle cell disease must be careful when participating in activities that may make it more difficult to breathe. These activities include playing sports, scuba diving, flying in airplanes, or having medical procedures that require anesthesia. They must also be careful when exercising in hot weather or at high altitudes (such as in the mountains). It is very important for people with sickle cell disease to get plenty of oxygen. Not having enough oxygen in the body can cause an episode or crisis.